

What are family member experiences of the resuscitation of a relative?

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Background:

A systematic review was carried out which aimed to gain insight into the feelings and perceptions of family members who witness an adult family member resuscitation. Little is known about family member's experiences and their needs and priorities. Resuscitation is a complex and highly emotive situation but guidance for Paramedics to support families either in the decision making process or to remain present is limited. Policy developments around improved and shared decision making are not evident in any guidance for resuscitation for Paramedics. Paramedics have always been involved in resuscitation in the family home but as they remain on scene for longer periods it is important that the issue of family participation is addressed and specific guidance produced to enable Paramedics to offer more focussed and enhanced support to them and utilise the family members in the decision making process which is a requirement from recent policy developments.

Methods:

A systematic review methodology was used to examine primary research studies from a qualitative perspective. This enabled a line by line examination to determine themes across and within the studies to inform a 'meta-synthesis' of the studies selected for this review. This resulted in four main themes emerging from the analysis of over 34 smaller themes that were re-categorised and sub themed into major topics for further analysis and discussion to formulate implications for practice and further research.

Findings:

Four themes emerged from this study:

- Families expect competent and professional care
- Families wanted to remain connected to their loved ones and be present throughout the resuscitation;
- Families wanted to share and contribute information to the decision making process
- Families perceived and experienced actual barriers to them being present.

Key Words:

- Family presence
- Relative(s)
- Resuscitation
- Paramedic

Literature & Policy Drivers

There were 60,000 resuscitation attempts in England in 2013, 80% were outside of hospital and 20% in hospital (NHS England, 2014). The most likely responders to events out of hospital are paramedics (Blaber, 2012). Paramedics provide resuscitation care for patients and families in out of hospital cardiac arrests and in those situations, families need a great deal of support to manage their emotions as they may have to come to terms with the sudden and often unexpected consequences of resuscitation (Leung and Chow, 2012).

In out of hospital cardiac arrest the reliance on support during such an event may be more acutely felt by families as they often have little choice on who is present, particularly those in a public area and rely on the expertise and skills of the Paramedic to support them (Blaber, 2011). The Paramedic is unable to supply the comprehensive range of support that is available in the in-hospital context without a multi-professional resuscitation team to draw from (Williams, 2014). This is a challenge for Paramedics as the same times they are required to provide lifesaving interventions (Gaskin, 2014). The context in which Paramedic care has changed significantly within the function of their major employer, NHS Ambulance Services, as they have moved from a transport service to a dynamic decision based service

(Williams 2014; JRCALC, 2014). This change in practice highlights the need to develop policy and guidance for practice.

Little is known about the actual experiences of resuscitation by family members during such events and a substantial body of literature focuses on the legitimacy of family presence rather than their needs or priorities during such episodes of care. Clear evidence, from qualitative and quantitative studies report overwhelmingly family members should be present (Doyle et al, 1987; Eichorn et al, 2001; Hanson and Strawser, 1992; Leung and Chow, 2012). The benefits include improved coping strategies with death to fewer reported psychological long term issues (Fulbrook et al, 2004; Monks and Flynn, 2014).

Guidance exists from the Resuscitation Council (1996) and RCN (2002) but to date this has not been consolidated in either a NHS wide policy or more local publications in individual trusts (Thoren et al, 2010). The policy drivers for practice regarding resuscitation should guide practice but they appear to not reflect the current context of resuscitative care. The Resuscitation Council (1996) policy that was written in 1996 does not consider that patients' are more actively resuscitated outside of hospital. The Resuscitation Council (1996) policy assumes that all resuscitative efforts are exclusively carried out in the hospital context. Paramedics offered a 'scoop and run' and transport service at the time of publication, however, as a more intensive and resuscitative care team in 2016 some 20 years later this requires a more complex decision making process rather than immediate transport (Blaber and Harris, 2011). The evidence suggests that families want a far more active role in that decision making process than was considered necessary or desirable in the past as a result of many changes to practice and policy.

The Resuscitation Council (1996) and RCN (2002) reflect practice at the time and they were formed mainly as a result of the well-publicised poor practice around paediatric death (Benjamin et al., 2004). They talked in depth about paediatric resuscitation and provided in depth guidance for paediatric patients but adult patients were almost referred to in passing. The RCN (2002) guidance suggests families should be allowed to be present but only after consultation with the senior doctor or nurse. This does not reflect the current policy of transparent shared decision making

(DH, 2012, 2013b). Unfortunately, The RCN (2002) guidance is the only professionally led guidance for practice. The College of Paramedics (2014) curriculum framework does not mention this neither does JRCALC (2014) guidance for practice. Furthermore, the RCN (2002) guidance makes the assumption that all resuscitation occurs in hospital despite 80% of all recorded resuscitations occurring outside of hospital (NHS England, 2014).

The RCN (2002) and the Resuscitation Council (1996) guidance appear limited and the scope of both documents appears to apply only a small number of current resuscitations. The Francis (DH, 2013a) and Keogh reports (DH, 2013b) highlighted the lack of family participation in decisions in emergency care as particular issue and it would appear timely to review such guidance for practice. The '6Cs' (caring, compassion, competence, communication, courage, commitment) provides a clear platform for healthcare professionals to drive this policy within practice to ensure families are included in a transparent and honest process of decision making (DH, 2012).

Methods: Data collection

The aim of this study was to gain insight into the experiences of the resuscitation of a relative from the family member perspective and consider what implications this may have on Paramedic practice. The diversity of evidence collected from a systematic study was selected as the most appropriate methodology as it would enable a much deeper understanding of the experiences of families rather than a small scale primary research study. Interpretive qualitative research was selected as the most appropriate evidence for this study as those types of studies seek to understand and interpret the human experience in context. A number of key words were chosen to interrogate the various databases selected for this study can be found in Table 1. The key word searches were selected using an adapted PICO search strategy suggested by Parahoo (2014).

Table 1: Key Word Searches

Population	Issue	Outcome(s)
Family Relatives Loved ones	Resuscitation CPR Cardiopulmonary resuscitation	Experiences Perceptions Feelings Views Understanding

In order to provide more focus to the study inclusion/exclusion criteria were applied to ensure that only those studies that focused exclusively on family experiences were included. In the methodological context this would increase the trustworthiness and therefore the transferability of the findings of the study to practice. The criteria for inclusion can be found in Table 2. This ensured that only adult resuscitation and the experiences of family members were captured for this study.

Table 2 – Inclusion / Exclusion Criteria

	Include	Exclude
Population	Adult patients (≥ 18 years). Family / Relatives / Loved Ones	Any person without a familial connection to the patient.
Issue	Resuscitation / CPR / Cardiopulmonary resuscitation	End of life care Palliative care

Outcome	Experiences Perceptions Feelings Views Understanding	None
Type of Study	Qualitative Studies	Quantitative Studies Letters Commentary Discussion papers Conference papers

The databases selected to search for the evidence included MEDLINE, CINAHL, EMBASE and AMED. They were selected because of their specific focus on healthcare and their relevancy to the focused question. The study also examined the 'grey literature', which identifies studies without formal peer review, those in progress, or those that had not met the criteria of specific publishers. They were also useful for further references and signposting to relevant documents. This identified 84 studies for potential inclusion in this study.

Data Analysis:

The 84 studies found from the comprehensive search were analysed using a two stage selection process. The first selection involved reading the abstract and title to determine if they met the criteria which resulted in 67 studies being discarded and 17 being put forward for the second stage. The second stage involved a full read of the studies from the first selection to determine how well they met the inclusion criteria. This resulted in the final selection of four studies as the evidence for this study. The studies were then further assessed for methodological quality using the RF-QRA quality assessment tool (Henderson and Rheault, 2004). This tool enables the reviewer to judge the trustworthiness using a quality assessment decision and grading tool. One study was assessed as Level one, the highest quality, one at Level two, one at Level 3 and one at Level 5 the lowest quality study.

The final four papers selected for this study were:

Quality Assessment: Level 1: Study Number 75

Hung, MS, Pang, SMC (2011) 'Family presence preference when patients are receiving resuscitation in an accident and emergency department'. *Journal of Advanced Nursing*, 67(1) p56-57

Quality Assessment: Level 2: Study Number 29

Leske, J.S., McAndrew, N.S., Brasel, K.J. (2013) Experiences of Families When Present During Resuscitation in the Emergency Department After Trauma. *Journal of Trauma Nursing*, 22 (5) p77-85

Quality Assessment: Level 3: Study Number 78

Weslien, M., Nilstun, T., Lundqvist, A., Fridlund, B (2006) Narratives about resuscitation – Family members differ about presence. *European Journal of Cardiovascular Nursing*, 1(2) p68-74

Quality Assessment: Level 5: Study Number 3

Wagner, J, (2004) Lived experience of critically ill patients' family members during cardiopulmonary resuscitation. *American Journal of Critical Care*, 13(5) p416-420

The results from those studies indicated there were 34 themes and furthermore there were a number of key commonalities across the studies. The quality assessments of each study examined the length and duration of data collection as part of the credibility assessment of the studies presented. It would appear that regardless of the data collection period the themes extracted from each study are broadly similar. The demographic and biographic information from each study also do not appear to have had any significant impact on the themes identified by family members as important.

The results were analysed and further synthesised to identify commonality of findings and meanings. A judgement was made by the reviewer following line by line examination of themes about those with similarities and common findings. New themes were formed and from the synthesis of results and merged into larger

headings. This resulted in four main themes being presented as evidence for this study.

- Competent and professional care
- Remaining connected
- Knowing the patient
- Barriers to presence

Table 4 – Thematic Analysis of Results

Theme	Study	New Theme
To submit or ignore the guidance of healthcare professionals	78	Competent and professional care
You do your job	3	
Role of the healthcare professionals to “fix” patient	3	
Multiple people helping patient	29	
Completion of many tasks and “assessment of the damages”	29	
Multiple people helping the patient	29	
Professionalism and team work	29	
Ensure the team is doing its job	29	
Role of family members to protect and support the patient	29	Remaining connected
Be in close proximity to provide physical and emotional comfort	29	
Being emotionally connected to the patient	29	
Providing emotional support to the patient	75	
Maintaining relationships with the patient and others	75	
To be caring for the good of oneself and others	78	

Recognising subtle changes something's wrong	3	Knowing the patient
Provide information to the medical team and other family	29	
Knowing the patient	75	
Recognising the patient's health condition	75	
Keeping informed about what is going on	75	
Being engaged in what's going on	75	
Providing information to the resuscitation team	75	
Experience and knowledge of resuscitation	78	
Should we stay or should we go?	3	Breaking down barriers to presence
Breaking the rules phase	3	
Here and now phase	3	
Perceived inappropriateness	75	
Perceived inconvenience	75	
Perceived prohibition	75	
Recognising the emergency department procedures	75	
Being afraid of disturbing resuscitation efforts	78	
To be dependent on the interplay between trusting oneself and advocating the patient	78	
To be sensitive to one's own emotions and to be reasonable	78	
Healthcare professionals	78	

Findings:

The four themes found and identified for this review indicated priorities for family members during resuscitation event and all of them relate to family member expectations of healthcare professionals (Wagner 2004; Leske et al, 2013; Hung and Pang, 2011; Weslien et al, 2006). There were no studies found that examined the

pre-hospital or out of hospital care of patients and the findings related entirely to the in-hospital perspective. The author of the study has attempted to draw some comparisons with pre-hospital care and make some suggestions as to how appropriate or how they could be interpreted for such practice.

The existing guidance for practice does not suggest family members should be excluded but discusses a process of permission of entry and rules of engagement which were contrary to the findings in this study (Resuscitation Council, 1996; RCN, 2003). The recent policy developments following the Mid-Staffs inquiry and the care and compassion agenda from NHS England requires healthcare professionals to plan holistic care centred on patients and their families (CQC, 2015; DH, 2013a, DH 2013bb; Gaskin, 2014). It would appear from the themes in the papers for this study this may be a challenge for healthcare practitioners, in particular Paramedics, as families still report there are barriers to presence.

Thematic Analysis: Competent and professional care

The first theme related to how family members viewed and experienced the care of their relatives. Three of the four studies highlighted the need for health care professionals to provide competent and professional care. Leske et al, (2013) found that family members expected healthcare professionals to work in an expert team dedicated to ensuring that their relative received the best care. This is illustrated in an extract below:

‘All hands on deck...many doctors around the patient...there was a lot of staff, twenty plus staff members working in the room’

(Leske et al, 2013; p80 Col 1, Lines 31-36)

This is perhaps relatively straightforward in the hospital setting but in pre-hospital care could pose a challenge. Interventions and procedures give some visual comfort to families and this is widely reported in the literature (Monks and Flynn, 2014; Duran et al, 2007). The challenge for the Paramedic as the only person authorised to make such interventions is to balance this with the family expectation to keep them informed, discuss treatment options and decisions. This is illustrated from an in-hospital context below:

Theme 2: Remaining Connected

The second theme found related to family members being connected to their relative during the resuscitation process. Family members express an even greater need to be as close to their relative as possible as they felt it was their role to support the emotional wellbeing of their relative and were reluctant to devolve this responsibility to the healthcare professional (Leske et al, 2013; Hung and Pang, 2011; Weslien et al, 2006). Families believe there is a clear distinction between the emotional care that they should provide and the professional care that they expected to be delivered by healthcare professionals. Those feelings are clearly demonstrated in an extract from one of the studies:

'It was helpful to be able to reassure my husband...my son new I was there...it helped him not to worry...I needed to be there it was very important to me that she (sister) knew I was there, very important.'

(Leske et al, 2013; p82, Col 2; Lines 7-10)

Not all families want to stay or even be in close proximity during the resuscitation event, it should not be assumed that being present during resuscitation is the best for everyone and the person who acts as the liaison between the family and the resuscitative event should ascertain their wishes as soon as practicable. This may be difficult in pre-hospital care but nonetheless every effort should be made to do so. This point is illustrated in an extract from one of the studies:

'I think that staying is different for every person...some people couldn't do it. I was in shock and that kept me calm and made me able to stay with him. I was glad he knew I was with him all the way. I have dreams...it all flashes on me.'

(Leske et al, 2013; p82, Col 2, Lines 23-39)

Benjamin et al (2004) and Chapman et al, (2013) suggest that healthcare professionals take a particularly paternalistic view of resuscitation and believe it is unnecessary for family members to be there. If it is not the emotional issues that concern families they perceive themselves as getting in the way of the health care professional (Hung and Pang, 2011; Weslien et al, 2006; Wagner, 2004).

Healthcare professionals should ensure that family members are enabled to remain

connected even if it is more difficult or there is a perceived lack of space to accommodate them.

'I could stand to the side if I was allowed in, and would not inconvenience them (the resuscitation room). Though I could not help...I think both of us would have felt better psychologically if I had been there. If offered the option in future I would stay there to be with her.'

(Hung and Pang, 2011; p62 Col 2, Lines 17-21)

Theme 3: Knowing the patient

This was one of the strongest themes in the study, families felt they had vital information about their relative that could contribute to the success of the resuscitation event or speed up the decision making process (Wagner, 2004; Leske et al, 2013; Weslien et al, 2006; Hung and Pang, 2011). They want to be included or considered as part of the resuscitation team (Wagner, 2004; Hung and Pang, 2011; Weslien et al, 2006). This is illustrated in the extract below:

'I can inform (the staff) about something that is not written in the medical record. It is not easy (for the staff) to read that (medical record) in a second. They read that he had undergone coronary bypass. I could inform them that four vessels were replaced and that was important information. Therefore I wanted to be there (in the resuscitation room) if any questions should be asked.'

(Weslien et al, 2006; p71 Col 2, Lines 28-34)

The Francis (DH, 2013a) and Keogh reports (DH, 2013b) both recommended significant changes to policy and require a more shared decision approach in practice and also called for more care and compassion to be demonstrated by practitioners. Family members in this study expressed a need to share information which they felt was vital to speed up the process of resuscitation and without it this may have caused an unnecessary delay.

'I needed to make decision for him...staff needed to know his history, medications, and insurance and he wasn't able to answer.'

(Leske et al, 2013; p82 Col 1, Lines 19-23)

Duran et al (2007) and Jabre et al (2012) found family members felt it was inefficient of the team to keep coming back to them to ask questions when they could be present and give immediate answers. Healthcare professionals may prefer to keep families in a waiting area (or in an adjacent room in the pre-hospital care context) to filter knowledge and prepare themselves for difficult questions or bad news (Eichorn et al, 2001; Myers et al, 2000; Robinson et al., 1998). The information and experiences held by patients family members they believe could ensure the decisions taken by the resuscitation team are made more collaboratively and are based on the most up to date and appropriate information (Hung and Pang, 2011).

‘She received treatment inside the resuscitation room....I recognised all the procedures... The doctors prescribed a chest X-ray...Once the films were seen by the doctor she was asked to be admit then. She is admitted to the medical ward on the 14th, 15th, or 16th floor two or three times a year.’

(Hung and Pang, 2011; p62 Col 3, Lines 9-15)

Theme 4 – Barriers to presence

This has been reported as a separate theme even though many of the issues are connected to the previous three themes. The reasons for this is to raise Paramedics awareness of the perception of family members about how local rules may ensure smooth running but they are perceived by family members as significant barriers to presence (Macmahon-Parkes et al, 2008). There was a feeling from family members that they were secondary and almost separate or outside of the process of resuscitation and were perceived as an inconvenience. Prohibition and exclusion in addition to several barriers to admission to the resuscitation room were of particular concern. The RCN (2002) guidance still refers to family members being ‘allowed’ to be present if they meet certain conditions and the power to make such a decision lies with the senior doctor or nurse. The family member perception about specific rules is illustrated in an extract from one of the studies:

‘Family members where permitted to break the rules, both formal and informal, to be with their loved one, but only after the patient’s condition was stabilized. The formal rules included such things as the regulations posted in the institution about the permissible hours for visiting patients. The informal

rules were the discretionary rules that individual nurses made about families visiting.'

(Wagner et al, 2004; p418 Col 2, Lines 5-12)

Patient studies confirm they believe it is their family member's right to be present but are worried about how they will cope with their emotions and this may appear as being difficult or demanding (Thoren et al., 2010). Families accepted they may be emotional but the studies point out this may be the last time they see or spend time with their loved one and being present, regardless of the rules it f critical importance (Wagner, 2004; Hung and Pang, 2011; Weslien et al, 2006). This is illustrated in the extract from one of the studies...

'I really understand that one is not allowed to be in there. I really do. I believe that always when you lose someone, it doesn't matter how much one has done and told, which I did for my husband, how much I loved him. You just want to say that once more.'

(Weslien et al, 2006; p72 Col 1, Lines 18-22)

The wider literature suggests families are often in a difficult situation having to make a decision to stay or go without while controlling emotions and feeling unsupported by healthcare professionals (Macmahon-Parkes et al., 2008). The orderly routine of critical care and the imposition of rules seem at odds with providing compassionate care (DH, 2012).

Limitations of this Study

This study was based on a limited number of studies, the optimum number of studies considered to influence practice is between six and eight and this study only found four. The trustworthiness of this study is therefore potentially limited and the quality of the recommendations should be noted with some caution. This may be directly related to the lack of existing literature or the inclusion criteria. The studies selected for this review related only to evidence found from an in-hospital perspective and are not directly related to Paramedic or pre-hospital care practice.

Implications for Practice

The study found that family members would like to be given the option of being present but need the support of healthcare professionals to enable them to make an informed decision. Family members should be accommodated during the resuscitation event and the appropriate space should be made for them to remain as close to both physically and emotionally to their relative. Expert knowledge from family members about their relative's medical history, value and beliefs should be listened to and taken seriously by a members of the team. Practitioners should make it possible for family members to be present and any local rules or policies that currently prevent family member presence should be reviewed. Family members rely on the ongoing support and guidance from healthcare professionals to make informed decisions but this study acknowledges that Paramedics may need further education and training to fulfil their expanded role in supporting family members to be present. The recommendations of this study are based on the themes produced from the evidence found to support this study.

- Family presence should be considered as routine practice in adult resuscitation.
- Paramedics and their employing organisations should consider how best to include family members in adult resuscitation.
- Clearer guidance for practice should be considered from JRCALC, employers and the professional body.
- Resuscitation teams should consider the appointment of a key individual in the team to support family presence and ongoing support, whether this is the Paramedic, ECA or another team member would be the subject of further research.
- A review of current policy and professional guidance for practice to reflect the current context of resuscitation care and inclusion of family members.

Conclusions

The findings of the systematic study suggest family members have as many needs and priorities during resuscitation as their relatives who are being resuscitated.

Family members consider healthcare professionals to be central to providing professional and competent care, ensuring they are kept informed and enabling them to make choices and support to make ongoing decisions and contribute to the care of their relative during resuscitation.

Healthcare professionals are also viewed as barriers to family presence and should recognise that families perceive professional rules of engagement as potentially harmful and negative. Families want to be seen as an integral part of the team and viewed as making as valuable a contribution to the progress and decisions taken during resuscitation. This systematic study has demonstrated that there is a lack of evidence to support family presence during adult resuscitation and that further evidence from a UK based study could inform the revision of current policy and professional guidance which does not reflect recent changes in context.

Future Research

Further research is needed on the experiences of family members during resuscitation in particular within the UK for wider influence on NHS policy.

Furthermore the uniqueness of the Paramedic context identified earlier requires further specific research about how the recommendations of this study could be implemented or amended for that specific context to contribute to the evidence based for this topic and the development of additional or enhanced practice guidance.

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